

**TESTIMONY
Of
Michael K. Tobin
Before the Public Health Committee
Of The
Connecticut General Assembly**

February 20, 2013

Madame Chairpersons and Honorable Members of the Public Health Committee, my name is Michael Tobin. I am here to testify in support of House Bill No. 5979, "An Act To Establish A Task Force on Alzheimer's Disease". The focus of my testimony will address a lesser acknowledged impact of Alzheimer's Disease, which should be included in a general Statewide Plan. I am referring to Younger-Onset Alzheimer's, which affects persons ages 45 to 65. The effects of this dementia carry a different burden to a family dynamic. It is genetic in its form, with the dominant gene "Presenilin 1" passed on through generations at a 50% risk, and usually comprises 10% of the total cases. It is a progressive disease, which over time will diminish and destroy all cognitive function within the person, causing death from the depleted immune system. It also places the caregiver(s) in a serious and complicated financial strain to manage costly maintenance prescription medications (\$1,000 per month), and for in-home or outside day care. In the long run, the State becomes expense-involved when the client requires nursing home placement, and the costs need to be covered by Medicaid Title 19.

I speak from personal experience, as my wife was diagnosed with Younger-Onset in 2004 at age 49, passing away in 2008 at age 53. There is a very strong family history on the paternal side of her family relating to the disease. Her father and his brother passed away in the early 80's, a sibling cousin passed in 2009 at age 52, and her sibling sister is still living with a diagnosis at age 53. All of the previously mentioned family members were/are carriers of the dominant gene, confirmed by genetic testing. And in casual research done by myself, the dominant gene may

have been existent in prior generations, but was undocumented medically. My deceased wife was also a confirmed carrier of the dominant gene, and my two sons, aged 19, are at risk for inheritance.

There are many issues that will be required to be included in a General Statewide Plan. Individual and Family counseling, respite programs for the working spouse, respite care for the client, should be inclusive and considered by the task force in the establishment of the Plan. Also, any form of local research support should be a provision. Finally, building and expanding workforce capacity is a concern.

Thank you for listening to my story and my reasons for supporting the proposed House Bill 5979, and for the opportunity to testify before you. I would be happy to answer any questions at this time. Please feel free to contact me at any time with any future questions or concerns.

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